Ontario
Advisory Council for
Disabled Persons

Independent Living

THE TIME IS NOW

**A discussion paper
on the future of
independent living assistance
in Ontario**

March 1988

INDEPENDENT LIVING - THE TIME IS NOW

A DISCUSSION PAPER
ON THE
FUTURE OF INDEPENDENT LIVING ASSISTANCE
IN
ONTARIO

Prepared by

ONTARIO ADVISORY COUNCIL FOR
DISABLED PERSONS

MARCH 1988

ISBN 0-7729-3601-3

PROCLAMATION OF THE DECADE OF DISABLED PERSONS

by the

GOVERNMENT OF ONTARIO

JUNE 1986

PRINCIPLE I

"The dignity, independence and potential of persons with disabilities will be respected in all aspects of life"

PRINCIPLE V

"Services and Programs will be aimed at integrating persons with disabilities into existing social and economic structures"

INDEPENDENT LIVING - THE TIME IS NOW

A DISCUSSION PAPER ON THE FUTURE OF INDEPENDENT LIVING ASSISTANCE IN ONTARIO

MEMBERS OF COUNCIL

Mr.	Ronald W. McInnes (Chairman)	- Toronto
Ms.	Karen Glen (Vice-Chairman)	- Toronto
Mr.	Robert E. Loveless (Vice-Chairman)	- London
Mrs.	Beryl Potter (Vice-Chairman)	- Scarborough
Mr.	Rodney Carpenter	- Ottawa
Mr.	Jean-Remi Champagne	- Ottawa
Mr.	Aldo Colangelo	- Downsview
Ms.	Rosemari Comisso	- Windsor
Mr.	Haile Selassie Girma	- Toronto
Ms.	Sharon Hoenen	- Peterborough
Mrs.	Anne Musgrave	- Toronto
Mr.	Irvin Osborne	- Chelmsford
Dr.	Peter Playfair	- Iroquois
Dr.	Gavin L. Shanks	- Kingston
Mrs.	Nancy Stone	- Niagara Falls
Ms.	Mary Lou Ware	- Ottawa
Mr.	Colin Wasacase	- Kenora

Council Staff

Mrs.	M. Tate	- Executive Officer
Mr.	A. Moore	- Research Assistant
Mr.	R. Kirkconnell	- Research Assistant

Councils' Offices:
Suite 203
700 Bay Street
Toronto, Ontario
M5G 1Z6

Honourable Remo Mancini
Minister Responsible for Disabled Persons

We are pleased to present to you this discussion paper on the future of independent living assistance in Ontario entitled Independent Living - The Time Is Now.

Members of Council wish to acknowledge the assistance received from many organizations and individuals in the preparation of the paper. The co-operation of staff in the policy unit of the Office for Disabled Persons and the Services for the Disabled Branch of the Ministry of Community and Social Services has been greatly appreciated.

Ronald W. McInnes
Chairman
Ontario Advisory Council
for Disabled Persons

Robert E. Loveless
Chairman
Committee on
Independent Living

TABLE OF CONTENTS

	Page
EXECUTIVE SUMMARY	i
CHAPTER I - INTRODUCTION	1
CHAPTER II - CURRENTLY AVAILABLE PROGRAMS	4
The Family	5
Institutional Settings	7
Group Homes	8
Workers' Compensation Board	10
Veterans Independence Program	11
Chronic Home Care	12
Homemaker Services	13
Integrated Homemaker Services	14
Orders-in-Council	16
Respite Care	17
Support Service Living Units	18
Outreach Attendant Care	21
CHAPTER III - TOWARD INTEGRATION IN ONTARIO	25
What Independent Living Assistance Means	27
Directing and/or Managing Independent Living Assistance	29
Housing	33
CHAPTER IV - FUTURE DIRECTIONS FOR INDEPENDENT LIVING ASSISTANCE IN ONTARIO	35
Support Service Living Units	36
Outreach Attendant Care	37
The Direct Funding Option	39
Funding of Family Members or Significant Others	42
Brokering	45
Advocacy	49
Independent Living Centres	49
Independent Living Assistance in the Workplace	50
CHAPTER V - EDUCATION	52
The Transition to Independent Living	52
Training of Independent Living Assistants	56
CHAPTER VI - CONCLUSION	62
END NOTES	65
BIBLIOGRAPHY	I

EXECUTIVE SUMMARY

This paper was written by a Council comprised of seventeen people who live in communities across the province and have an active interest in the provision of independent living assistance to disabled persons. Independent living assistance is defined here as assistance with tasks "that individuals would normally do for themselves if they did not have a disability".(6) The paper is based on the philosophy that all citizens of Ontario, whether they are disabled or not, should have the freedom to choose the most appropriate lifestyle for themselves.

The paper explores present methods of obtaining personal assistance in Ontario. The conclusion reached is that while existing programs serve the needs of many disabled persons, they are nonetheless restrictive and do not permit all consumers the freedom and independence required to become fully integrated into society. While no two disabled persons require the same type of independent living assistance, Council believes individuals generally fall into one of three groups. This takes into account differing functional levels and degrees of control which individual consumers wish to assume over the assistance they receive.

Council argues that the present Support Service Living Unit and Outreach programs need to be altered and expanded significantly to meet the growing needs and expectations of disabled persons. Funding for services presently offered under these programs needs adjustment and Council sees an expanded role for both programs in providing assistance to disabled persons in various settings, such as the work place.

There is a missing link in the provision of independent living assistance in Ontario: a direct funding option which would allow the consumer to direct and manage his or her own assistance, hiring whomever he/she chooses to act as his/her paid assistant. However, Council does not see this as a carte blanche system. Annual budgets will have to be developed and reviewed to ensure that the monies flowed to consumers are being used prudently.

The paper explores ways in which Independent Living Centres and brokering can contribute to the process of linking consumers with independent living services. Issues surrounding the need for education of consumers and training of independent living assistants are also examined.

The recommendations of Council appear throughout this report. For easy reference they are re-stated here in numerical order.

RECOMMENDATIONS

CHAPTER III - TOWARD INTEGRATION IN ONTARIO

1. That independent living assistance be provided in a flexible manner so that the needs of all persons with disabilities will be met wherever they choose to live in the community.

2. That independent living assistance be available in all settings of daily life: at work, at school, on business trips, for recreational activities and vacations.

3. That independent living assistance be provided as a non-medical, comprehensive community-based service.

4. That recognition be made of three varying levels of abilities and preferences of persons requiring independent living assistance:

    - Those who can direct and/or manage their own assistance;
    - Those who with development of their skills, can direct and/or manage their own assistance; and
    - Those who, for whatever reason, are unable to direct or manage their own assistance.

CHAPTER IV - FUTURE DIRECTIONS FOR INDEPENDENT LIVING ASSISTANCE

5. That future Support Service Living Unit projects should not be of a size that they become mini-institutions.

6. That service recipients should participate more actively in the management and administration of Support Service Living Unit projects.

7. That greater flexibility should be incorporated into the budget process for Support Service Living Unit projects.

8. That every effort be made to improve the design of the Outreach program and to increase its availability in all areas of the province.

9. That mechanisms be developed to improve the flexibility and portability of the Outreach program in order that independent living assistance can be provided to consumers outside their homes.

10. That the government of Ontario design and initiate a pilot project within the public service to deliver independent living assistance in the workplace.

11. That consumers of independent living assistance who wish it should be provided with the funds to acquire, manage and direct the services that meet their unique support needs.

12. That annual budgets should be established for each individual, subject to speedy review, to allow for changing service needs.

13. That the Review of Support Service Needs being undertaken by government with interested groups and individuals should continue to develop optional methods of flowing funds to individual disabled persons who are able and willing to manage and direct their services.

14. That individuals in receipt of independent living assistance should be enabled to pay anyone, including family members or significant others, for the provision of support services.

15. That the government of Ontario, in consultation with consumers and interested community groups, explore the concept of brokering and develop models to be tested in both rural and urban areas of the province.

16. That the government of Ontario encourage the development of Independent Living Centres in rural and urban regions of the province.

17. That the Ontario Government, in consultation with consumers, unions and employers, develop and test methods of providing independent living assistance in the workplace.

CHAPTER V - EDUCATION

18. That educational programs, designed to enhance the ability of individual consumers to direct and manage their support services be made available across the province in Transitional Living Centres, Independent Living Centres or Community Colleges.

19. That those employed as independent living assistants be accorded all the rights of an employee, including access to job training programs and job advancement where possible.

20. That funding, whether to individuals or organizations providing independent living assistance, should be reviewed annually on a province wide basis in a manner similar to that presently proposed for Visiting Homemaker Services. The review should allow for some merit and cost of living adjustments within set salary scales.

21. That the portion of funding allocated for wages, benefits and training of staff should be protected within the budget from encroachment by other expenditures.

CHAPTER I

INTRODUCTION

We live in a society which holds freedom to be one of its most valued principles. Freedom can be interpreted in many ways. One of its most fundamental components is the right to self-determination. This is what this paper is about---the right of all persons to direct their own lives and choose the most appropriate lifestyle for themselves.

The Ontario Advisory Council on the Physically Handicapped was formed in 1975 by Order-in-Council to advise the Government of Ontario on matters pertaining to the well-being of disabled persons in the province. As of April 1987, Council's name was changed to the Ontario Advisory Council for Disabled Persons.

In 1982, Council released a Position Paper on Individual Attendant Care. While much of that paper is still valid, times and attitudes have changed sufficiently to make it necessary for Council to review its position on this subject. In the five years since the first paper was issued, the community has identified many new needs and the government has developed new programs.

Because Council has received requests from consumers and service providers alike to give urgent attention to the issues surrounding the provision of independent living assistance, members decided to focus their work on this subject during 1987/88.

Council wishes to recognize major contributions in this area by many organizations. In addition to reviewing briefs and current literature, members met with concerned groups and individuals and held a consultation meeting in Thunder Bay specifically on this topic. It is apparent that a new, progressive philosophy is developing in all sectors of Ontario regarding independent living in the community. Members thank all who have shared their views on the subject with Council.

"Independent living assistance" is a more appropriate term than "attendant care". The Federal Sub-Committee on the Disabled and the Handicapped has developed a useful description of the independent living movement:

> "Independent living has been regarded as a cross-disability social movement. It emphasizes the philosophy that disabled persons themselves are best able to define their own needs, and with appropriate support, can direct the fiscal and human resources to respond to those needs. Independent living means being integrated as fully as possible into the community.

> The philosophy also encompasses the concept of "dignity of risk", which means that mentally and physically challenged people should have the opportunity to make their own decisions and even to risk making their own mistakes. The independent living movement has been a reaction to the total dependence on institutionalization and a sometimes paternalistic mentality".(1)

Council endorses this description and throughout this paper uses the term "independent living assistance" to replace the term "attendant care" used in the 1982 Position Paper. Independent living assistance covers the range of services required by people with disabilities in order to live independently and in the least restrictive environment possible.

CHAPTER II

CURRENTLY AVAILABLE PROGRAMS

Council is aware that there are a number of ways in which disabled persons obtain independent living assistance in Ontario. However, most sources focus primarily on the provision of personal care and do not provide adequate amounts of other types of assistance so necessary for independent living. As presently designed, these services do not allow consumers true independence through acquisition and control of the services received. Apart from criminal injuries compensation, personal injury damage awards by courts and private disability insurance, the principal means of obtaining assistance include:

a. the family;

b. institutional settings;

c. group homes;

d. Workers' Compensation Board;

e. Veteran's Affairs Programs;

f. Chronic Home Care/Homemakers Services;

g. Orders-in-Council;

h. Respite Care;

i. Support Service Living Units; and

j. Outreach Attendant Care.

The Family

No discussion of personal care would be complete without special attention being paid to the role of the family. Traditionally, most assistance delivered to disabled persons in Ontario has been provided by family members--most frequently parents, spouses or significant others.

The family continues to play a vital role in the provision of assistance to disabled persons. An evaluation of the Outreach Attendant Care Program conducted by the Ministry of Community and Social Services in 1986 showed that prior to receiving services under that program, almost 65% of clients were receiving assistance from family members.(2) In addition, a major survey of disabled Americans conducted by Louis Harris and Associates for the International Center for the Disabled in New York found that 72% of those surveyed received assistance when they needed it from relatives or friends.(3)

While there are no firm statistics available, it is believed the waiting lists for the Outreach and Support Service Living Unit programs are very long. The waiting lists probably do not include individuals who are inappropriately placed in chronic-care settings or

those who, discouraged by the apparent unavailability of services, have not applied to any program. There are also numbers of unidentified people living in areas of the province in which support services are either currently unavailable or lacking adequate co-ordination. It can therefore be assumed that the family still plays an active and important role in the provision of services to disabled persons.

There are problems associated with the expectation that the family will assume the function of providing assistance to a disabled family member. Society has changed over the years, and today many families are two-income or single-parent units. Economic problems and expenses associated with disability can put an unreasonable burden on the family and lead to family breakdown. Mistreatment and inappropriate institutionalization may be the result of this type of prolonged family stress.

It is a challenge to a family to assist a young person to develop the necessary life skills that are needed if that person is to become independent and integrated into the mainstream of society. Control and integration can be hindered when a disabled person is forced through lack of options to live in a loving but sheltered family situation.

Institutional Settings

For years, a large number of individuals in need of personal assistance were relegated to institutions such as nursing homes, chronic care and even psychiatric hospitals. There were various reasons given for this treatment. Essentially it was felt that disabled persons should be protected, could never be productive or be responsible enough to assume their place in society.

Many persons had feelings of discomfort when confronted with a disabled individual. Over the years and with the work and perseverance of many individuals and groups, these negative attitudes have diminished considerably in Ontario and the integration of persons with disabilities into the mainstream of society has become the stated policy direction at all levels of government.

However, even with new attitudes and the move toward integration, a disproportionate number of disabled persons still live in institutional settings for which funding is provided by the Ministries of Health and Community and Social Services. Because of the size and nature of these institutions, services to residents are

predominantly medically oriented and offer little opportunity for an individual to exercise control or direction.

While the Ontario government's stated policy of de-institutionalization is welcomed by those who see integration into the community as a priority, the development of community programs and services, including essential housing options, must be provided to enable those who wish and are able to move away from institutional settings to do so. Until community-based systems have been developed to meet the complex needs of individuals with multiple disabilities or severely challenging needs, some institutional accommodation will continue to be needed.

Group Homes

As Ontario moved toward de-institutionalization in the 1970s, group homes were developed. Group homes were viewed as necessary for those disabled children and adults who had lived in institutional settings throughout their developmental years and whose life skills had not been permitted to develop to a level which would allow them to function independently.

Whether as a transitional or permanent setting, group homes are extremely important for many individuals,

including developmentally disabled persons. A group home may be the most suitable setting and some individuals are often most productive and happy in such environments. However, a major concern remains that many individuals are placed in group homes when they could have their needs met in their own homes. This situation usually arises because of the lack of accessible housing and/or appropriate services.

The community believes that there is increasing reluctance to fund single-disability facilities. This is understandable, given the philosophical shift from segregation toward integration. However, government policy must remain flexible enough to allow for appropriate care of those with special needs. This may include persons who are both deaf and blind or have other multiple disabilities and for whom a group home may offer the best possible support.

The development of group homes depends on co-operation between municipal and provincial governments, and there has been opposition to building new facilities in appropriate locations within some communities. Zoning restrictions can lead to the inappropriate placing of group homes (such as in light industrial areas) which certainly does not lead to integration. Council believes that all levels of government must place greater emphasis on pre-planning to identify

appropriate locations for group homes, thus facilitating successful integration of the residents into a community.

Workers' Compensation Board

Persons severely injured in the workplace or in the course of employment can receive directly an attendant's allowance from the Health Benefits Branch of the Workers' Compensation Board. To qualify, the person must be totally disabled (as defined by the Workers' Compensation Board) and a review committee of the Branch determines how much compensation an individual will receive for support care. There are seven categories, the highest of which will provide the individual with approximately $1,000 monthly to purchase his or her own support requirements.

This plan is of a limited nature and designed specifically to cover work-related accidents only. The injured employee does not have to go to the courts and receives the benefit for which he/she is deemed eligible directly from the Workers' Compensation Board. The Board, in essence, is providing a type of protection for employers who cannot be sued by an employee who has applied to Workers' Compensation Board for compensation.

In 1986 Council advised the Government of Ontario that it believes the adoption of a Universal Disability Insurance Plan would benefit all persons, regardless of the nature or cause of disability. Such a plan should amalgamate funding from all existing disability compensation schemes in the province, including the Workers' Compensation Board, into a single comprehensive system.

Veterans Independence Program

This program, funded by the federal government's Department of Veterans Affairs, is aimed at helping veterans and their dependents maintain or improve their quality of life by assisting them to remain independent in their own homes or communities. Services under this program include:

1. Counselling and referral
2. Health Information
3. Care

Where care is needed, the program will attempt to provide it in the veteran's own home or community. Types of care may include:

1. Adult Residential Care
2. Ambulatory Health Care
3. Home Adaptations
4. Home Care
5. Nursing Home Immediate Care
6. Transportation

There are limits to the amount of funding this program will provide to qualified persons and, in some cases, the individual will be asked to make a contribution toward the costs of the services provided. Like the program offered by the Workers' Compensation Board, benefits are limited to a defined group of persons; namely, veterans and their dependents.

Chronic Home Care/Homemaker Services/ Integrated Homemaker Services

There are three similarly named programs funded by the Ministry of Health and the Ministry of Community and Social Services from which disabled individuals can obtain homecare/homemaking services. Eligibility criteria vary somewhat for each program but each is designed to provide some degree of personal care and housekeeping support.

1. Chronic Home Care

The Long Term (Chronic) Home Care program, which is administered by the Ministry of Health, is available to a person:

(a) who is chronically ill and/or has a functional disability (physical or mental);

(b) whose acute phase of illness is over;

(c) whose vital processes may or may not be stable;

(d) whose potential for rehabilitation may be limited, and

(e) who requires a range of medical therapeutic services and medical management.

To be eligible for the program, individuals must meet certain specific criteria, be insured under the Ontario Health Insurance Plan (O.H.I.P.) and be under the medical supervision of a physician.

Eligibility for the program is assessed by a Home Care Manager once every two months. A patient whose condition is in a state of change may be assessed more frequently.

2. Homemaker Services

The Visiting Homemaker and Nursing Services Program is primarily funded by the Ministry of Community and Social Services. This program assists in the maintaining and strengthening of family life during illness or absence of a parent or guardian. It also assists elderly, convalescent, handicapped, chronically ill or otherwise disabled persons to remain in their homes whenever possible. It is funded 80% by

the Province of Ontario through the Ministry of Community and Social Services, and 20% by the municipalities. Since not all municipalities choose to participate, the service is not universally available.

The program is administered by the municipalities who determine the extent and type of services required and obtain them from such organizations as the Red Cross, the Victorian Order of Nurses and the Visiting Homemakers Association. They may also obtain services from the private sector. Clients are means-tested for the services and if it is found that a client can afford to make a contribution towards the cost of the service, he/she is required to do so.

3. Integrated Homemaker Services

It is intended that the Integrated Homemaker Program for frail elderly and disabled persons will eventually be available across the province. The program will be expanded only in regions that meet the following criteria:

- a significant population of elderly residents;

- a well-established home care program;
- an ample supply of qualified homemakers; and
- a full range of community support services.

Delivered through the Ministry of Health's Home Care Programs, homemaker projects will provide a number of necessary services in the home for frail seniors and physically disabled adults whose activities are limited and who require assistance in order to remain in their own homes. Services such as assistance with personal grooming, meal preparation, laundry, shopping and light housekeeping duties are among the range of services offered under the program. Personal care offered under this program is of a very limited nature.

The provision of these services for the frail elderly and adult disabled persons is based solely on the need for service rather than financial or medical criteria.

The problems for persons receiving services under these programs are varied. Programs are not available on a universal basis across the province and where they are in place, no two regions appear to offer the same inventory of services. Where a consumer requires a

range of services, these are unlikely to be available through one program and the recipient is faced with the complicated task of accessing different programs for different services. This means that a number of service providers are in and out of the consumer's living space, which is not always desirable or convenient. The One Stop Access program, presently being tested on a pilot project basis, is intended to resolve some of these problems. Appropriately developed, this program could offer easier access for disabled persons to the full range of support services.

In addition, there are problems created by the inflexibility of some case managers and differing interpretations of program rules. The low wages paid to employees of these programs, the inevitable high employee turnover that results and training issues are also significant concerns.

Orders-in-Council

An Order-in-Council is a method which has been used in Ontario to fund an individual's independent living assistance needs. There are presently about a dozen persons receiving benefits in this way. The province determines the amount of services needed and an Order-in-Council is passed by Cabinet approving the required expenditures for one year. The services are

provided to the recipient by a third party non-profit agency on a contractual basis.

In 1986 the provincial government announced that this funding method would be phased out and those then receiving funds through Orders-in-Council would be transferred to other government programs. Although, in theory, individuals can still be granted Orders-in-Council in exceptional circumstances, this cannot be considered a "program".

Respite Care

Respite Care is defined as:

> "A service that provides periodic, short-term care to a dependent person for the purpose of providing an interval of respite for that person's parents, spouse or other primary caregiver(s)." (4)

Before the early 1970s, there was no relief for the caregivers of disabled persons who were and still are primarily family members. In 1974, the Ministry of Community and Social Services reviewed the Developmental Services Act and, as a result, the Ministry began to fund formal relief programs for families with developmentally disabled members.

Respite Care Programs often serve as an efficient method of giving relief to those providing personal services to disabled family members. Other alternatives, such as institutionalization, are far more costly than services provided under this program.

This program is not available in all regions of the province and, where it is, the scope of the services available often does not meet the needs of disabled persons. There may also be disabled persons who are either unaware of the program or who feel their need is not likely to be recognized.

Support Service Living Units

Support Service Living Units (S.S.L.U.), commonly referred to as "projects", date from the mid 1970s when the Ministry of Community and Social Services began to explore alternatives to institutionalization. As of March, 1987 there were 56 S.S.L.U. projects in existence in the province, serving 688 individuals.

A Support Service Living Unit project is organized by a non-profit community group or "agency". The agency assumes administrative responsibility for the provision of the assistance which the disabled adult residing in

the project requires with the basic activities of daily living, in order that he/she may live as independently as his/her disabilities permit. Accommodation may be in private apartments or in shared residences.

Support services from projects are designed for physically disabled persons who are:

- 18 years of age and over, (although someone 16 or 17 may be considered in exceptional cases);
- capable, or potentially capable, of directing their own care;
- in need of assistance with the activities of daily living;
- able to obtain their medical needs in the community; and
- unable at present to obtain the required care from home support programs.

Independent living activities which the Ministry of Community and Social Services will fund under this program are:

- mobility, transferring and positioning;
- meal preparation, eating, clean-up;
- rising, dressing, undressing, going to bed;
- washing, grooming, shampooing, toileting including bowel and bladder procedures-- e.g. catheter care;
- physical body control; and
- essential communication.

In addition to these activities, laundry, housekeeping, and cooking help may be provided. No services are provided under the program outside the recipient's home. The resident is responsible for his/her own shopping, banking and other activities outside the home. To be considered eligible for the program, the individual must be unable to have his/her needs met by other community services because of the intensity, irregularity or unpredictability of his/her requirements over a 24-hour period.

The problems associated with the Support Service Living Unit program are varied. Issues of concern include those that arise from the necessity to share services among project residents; for example, the requirement to fit into a schedule in which priorities may be determined by others and lack of flexibility. Services are, of course, only available in the residence and the resident cannot choose the staff person designated to assist him/her.

A major problem for both project management and the resident is the inevitable fluctuation in the level of services required. Clients may require more or fewer services from time to time and schedules are not easily adjusted to meet ad hoc needs of a resident. All these issues create scheduling and budgeting problems.

There is also the difficulty of designing mechanisms to protect the privacy, security and dignity of residents in S.S.L.U's while, at the same time, ensuring that those providing assistance have a clear understanding of their role and responsibilities. Varying salary levels, training and staff turnover are other problems that have been identified.

Support Service Living Unit projects work very well for many but have developed unevenly across the province, and are not available in all areas. An increase in the number of projects rather than an increase in the size of existing projects appears desirable, as does increased consumer participation in management through involvement in the administration of S.S.L.U. projects.

Outreach Attendant Care

The Outreach Attendant Care Program was first announced in the June, 1984 Provincial Budget, with the Ministry of Community and Social Services as the provincial ministry responsible. Its purpose is to provide personal care services, on a visitation basis (maximum of 90 hours per month), to physically disabled adults living in their own homes. As of March, 1987 there were 344 individuals receiving services under the Outreach Program.

When the program was conceived, it was designed to perform three functions:

1. To support families caring for physically disabled adults at home;

2. to complement existing community services; and

3. to enable low to moderate care persons currently residing in Support Service Living Units to move into the community.

The major services provided under the program are transferring (bed to wheelchair and vice-versa), assistance wit bowel and bladder care, bathing and washing and meal preparation. In fact, the hours of service provided to an individual have been known to exceed 90 hours where clearly determined needs have been demonstrated. While much depends on the flexibility of the Ministry of Community and Social Services area manager, the program has done a great deal to assist its clients in moving toward their goal of independent living in the community.

Provisional guidelines provide the only available basis for administration of the Outreach Program. As a result, the services available under the program are open to interpretation. For example, a number of service providers interpret tasks such as catheterization as a medical task since it is not covered by definitive guidelines. This is one example of the inconsistencies that can create a significant

problem when a recipient moves and the program in the area to which he/she has moved is not being interpreted in a similar manner and does not cover the same range of services that were covered under the individual's old program. Services offered under the program are only available at home and exclude the workplace, business trips, education, recreational activies and vacations.

Other problems with the Outreach program are the lack of services between midnight and 6 a.m. and the difficulty in co-ordinating Outreach with other services such as housekeeping and nursing. These programs operate on the basis of different eligibility criteria and differing hours of service. Too often this lack of co-ordination means the disabled person has to relate to a number of different agency staff moving in and out of his/her living space.

Many assistants are poorly paid, resulting in high turnover and associated increases in training costs. The part-time nature of much of the work also creates problems recruiting and retaining reliable staff. The hours which are often made available to staff in this program are insufficient to enable them to continue in this work.

When calculating the hours of service that can be provided to a client in his/her home, some Outreach

projects include the travel time taken by the independent living assistant. Some projects do not pay for enough travel time to fairly compensate those providing assistance.

In reviewing existing methods of providing personal care to disabled persons in Ontario, Council feels that although programs such as Outreach go a long way to encourage independent living, there are inherent problems with all the programs that stem from the following design flaws:

- Lack of portability - programs are strictly home-based.
- Geographic restrictions - not all programs and services are universally available across the province.
- Inequality in the provision of services in different locations.
- Lack of flexibility, vis-a-vis hours of service and scheduling.
- Lack of consumer control. The perception remains that the client must fit the program rather than that the program must change to accommodate the client's needs.
- Since dollars are finite, consideration of individual needs is downgraded.
- Inconsistency in the calculation of and reimbursement for travelling time of independent living assistants.

CHAPTER III

TOWARD INTEGRATION IN ONTARIO

Council believes the following philosophical guidelines should be at the heart of any independent living assistance program:

- **That community living be recognized as a fundamental right for all citizens of Ontario.**
- **That accessible services be created and expanded to meet the needs and expectations of active and participating people living independently in communities across the province.**
- **That consumers have the maximum control possible over the design and provision of their independent living assistance.**

These tenets reflect the principles of the Proclamation of the Decade of Disabled Persons. When disabled persons are provided with a full range of independent living services, the employability of the disabled and their ability to contribute to society will be enhanced. Surely such provision is appropriate in a just and caring society.

Council believes independent living assistance should be available to individuals with disabilities in all settings. If independent living assistance is available to consumers at home, at school, at work and on vacation, Council believes that dignity and quality

of life will be enhanced because disabled persons will be allowed to participate more fully in the mainstream of Ontario society. The impact of disability, the possibility of which confronts all Ontarians, will be mitigated.

In the last few years the provincial government has shown an increasing commitment toward integrating disabled persons into society. Council has long advocated this action but members also realize that integration is a hollow concept unless services and programs are actually in place to allow disabled persons to assume their place in Ontario society. Although some additional funding will be required, redistribution of dollars in existing programs and, ultimately, from the institutional sector as facilities are completely closed down, should be possible.

The concept of independent living has broad implications. As Adolf Ratzka indicated in his study of independent living and attendant care in Sweden: "attendant care services are the very key to a dignified and productive life in the community".(5)

All persons have the right to work and to have adequate and accessible transportation services, housing, social and personal relationships. The majority of Ontario

residents take these rights for granted. However, the pre-requisite for all the diverse activities of daily life for many disabled persons is the availability and provision of independent living assistance, even on a 24-hour basis if that is what is necessary to provide the maximum of independence and living options.

Council's vision for independent living assistance would allow disabled persons to achieve their personal goals by ensuring that services are provided to them in a flexible manner that can be tailored to the needs and abilities of individuals wherever they choose to live or work in the community.

WE RECOMMEND:

1. **THAT INDEPENDENT LIVING ASSISTANCE BE PROVIDED IN A FLEXIBLE MANNER SO THAT THE NEEDS OF ALL PERSONS WITH DISABILITIES WILL BE MET WHEREVER THEY CHOOSE TO LIVE IN THE COMMUNITY.**

2. **THAT INDEPENDENT LIVING ASSISTANCE BE AVAILABLE IN ALL SETTINGS OF DAILY LIFE: AT WORK, AT SCHOOL, ON BUSINESS TRIPS, FOR RECREATIONAL ACTIVITIES AND VACATIONS.**

What Independent Living Assistance Means

Emphasizing the need for flexibility, the World Institute on Disability in Attending to America: Personal Assistance For Independent Living has set out the parameters of what Council chooses to call independent living assistance:

"Personal assistance involves assistance with tasks aimed at maintaining well-being, personal appearance, comfort, safety and interactions within the community and society as a whole. In other words, personal assistance tasks are ones that individuals would normally do for themselves if they did not have a disability. Central to this definition is the precept that personal assistance services should be controlled by the user to the maximum degree possible.

These tasks may include:

1. personal maintenance and hygiene activities such as dressing, grooming, feeding, bathing, respiration and toilet functions including bowel, bladder, catheter and menstrual tasks;

2. mobility tasks such as getting into and out of bed, wheelchair or tub;

3. household maintenance tasks such as cleaning, shopping, meal preparation; laundering and long term heavy cleaning and repairs;

4. infant and child related tasks such as bathing, diapering and feeding;

5. cognitive or life management activities such as money management, planning and decision making;

6. security-related services such as daily monitoring by phone; and

7. communication services such as interpreting for people with hearing or speech disabilities and reading for people with visual disabilities." (6)

The classification as "medical" of certain tasks involved in independent living assistance, primarily bowel and bladder care and catheterization, has raised concerns with Council. To disabled persons, these are not medical tasks but are simply another part of daily living which should be treated no differently from other tasks. Every exemption from independent living

assistance creates an impediment to independence for a disabled person. If there is any risk (which we believe is minimal), it is one which a disabled person has a right to assume.

WE RECOMMEND:

3. **THAT INDEPENDENT LIVING ASSISTANCE BE PROVIDED AS A NON-MEDICAL, COMPREHENSIVE COMMUNITY-BASED SERVICE.**

Directing and/or Managing Independent Living Assistance

There is always a danger in trying to categorize people. This often leads to fitting individuals to programs and not programs to individuals. With this in mind, Council believes that the conceptual framework of independent living should ensure that from a range of community services, a personalized "menu" can be selected to suit individual needs. After long consideration, we believe that independent living assistance should be designed with the recognition of the abilities of certain broad groups of individuals and should provide a continuum of options that will allow the maximum flexibility for each person.

- Those who can direct and/or manage their own assistance.
- Those who with development of their skills, can direct and/or manage their own assistance;
- Those who, for whatever reason, are unable to direct or manage their own assistance.

The term "direct" is used in the sense of an individual's ability to indicate his/her service needs. There are many disabled persons who are, in addition, capable of "managing" as well as "directing" their own assistance, and with experience gained in transitional settings, the expectation is that many more people will prefer this option. "Managing" would include independent scheduling of care, hiring/firing of assistants and all the administrative functions and management responsibilities associated with being an employer.

For those who wish the flexibility of a completely independent lifestyle, the responsibilities of management do not present a problem. They would welcome the opportunity, which currently does not exist, to manage their own funding and services. Such an option would allow them to live wherever they choose and may well enhance their ability to find employment and thus contribute, through taxes, to the benefits they receive.

Other people, who can direct their own assistance, prefer not to "manage" their assistance and choose to live in their own home in the community obtaining assistance through the Outreach program. Alternatively, they may choose to live in a Support Service Living Unit project. Whether they receive

assistance through Outreach or an S.S.L.U., many lead busy lives moving through employment, school, home, volunteer and recreational activities. Such individuals do not wish to put scarce time and energy resources into managing the delivery of their independent living assistance. They prefer the security of knowing assistance will be provided in a manner which they can direct, leaving them free to give priority to other activities such as employment or education.

Another group of individuals are those who, with development of their skills, can learn to direct and/or manage their own assistance. For these persons the support offered in a transitional setting may be appropriate on a temporary basis. Working with brokers or Transitional Living Centres, these disabled persons can acquire life skills training that will enhance their ability to move to more independent living accommodation. The final group of individuals who, for whatever reason, are unable to direct or manage their own assistance may need to remain in a group home or a more individualized setting where, with support, they can achieve the maximum possible independence.

Persons who face specific difficulties associated with severe or multiple disabilities are very often among those who are unable to direct their own assistance and

will need accommodation and appropriate programs in facilities offering more intensive and intrusive support services. In spite of the trend toward de-institutionalization, it must be recognized that for a small number of physically disabled people, the need remains to provide them with higher levels of care. This may require a specialized group home or institutional setting. Such settings need to be creatively designed to be as homelike as possible, providing each individual with the maximum amount of dignity and opportunity for self-determination with respect to the assistance they require.

Acknowledging the different levels of abilities or preferences allows a diversity of needs to be recognized. It also permits a number of different programs to be developed to meet the varied needs of persons who require independent living assistance. Council firmly believes that such programs must be built on a social rather than a medical model.

WE RECOMMEND:

4. **THAT RECOGNITION BE MADE OF THREE VARYING LEVELS OF ABILITIES AND PREFERENCES OF PERSONS REQUIRING INDEPENDENT LIVING ASSISTANCE.**

   - **THOSE WHO CAN DIRECT AND/OR MANAGE THEIR OWN ASSISTANCE;**

- **THOSE WHO WITH DEVELOPMENT OF THEIR SKILLS, CAN DIRECT AND/OR MANAGE THEIR OWN ASSISTANCE; AND**

- **THOSE WHO, FOR WHATEVER REASON, ARE UNABLE TO DIRECT OR MANAGE THEIR OWN ASSISTANCE.**

Housing

In discussing the various programs which provide independent living assistance to disabled persons, the assumption has been made that appropriate housing is available. This is not always the case.

Affordable as well as accessible housing, in locations that are convenient to transportation and other necessary amenities, is not universally available across the province. In this respect Council regrets the decision by the Ministry of Housing to exclude housing, other than large apartment buildings, from certain of the barrier-free design provisions of the Ontario Building Code.

Even within individual apartment suites, the barrier-free design requirements are minimal and the recommendation of the Advisory Committee on the Ontario Building Code, Ministry of Housing, that apartment buildings contain "mobility-adaptable" units, has not been adopted. "Mobility-adaptable" units, if incorporated into the design of an apartment building,

can be transferred from accessible to general use with minimum difficulty and Council believes they would enhance housing options for everyone.

Council welcomes initiatives such as the recent changes to the Ontario Home Renewal Program For Disabled Persons but feels that the unmet demand exceeds current program limits. Commencing in Spring 1988, community-based organizations will be funded by the Office for Disabled Persons to operate, in five locations across the province, Homelink--housing information centres--to assist disabled persons to find suitable rental accommodation. Members will be watching the development of this program with great interest.

Council believes that people with disabilities face special difficulties in locating accessible and, of equal importance, affordable housing. Appropriate independent living assistance and appropriate housing are very much inter-related.

CHAPTER IV

FUTURE DIRECTIONS FOR INDEPENDENT LIVING ASSISTANCE IN ONTARIO

Chapters II and III of this paper provided a brief description of many ways in which disabled persons currently receive personal assistance in Ontario. They have also described the expanded concept of independent living assistance which Council feels is more in line with the needs and desires of disabled persons today. It is now time to look at future directions for independent living assistance in the province.

Council envisages a range of independent living assistance programs which will allow all disabled persons maximum control over the provision of services they receive and maximum freedom in their lifestyle.

Support Service Living Units and the Outreach program now meet and will continue to meet the needs of many who can direct their own care but choose not to manage the services they receive. However, these programs will need adjustment if they are to continue to develop positively.

Support Service Living Units

Notwithstanding the problems indicated earlier that are inherent to the nature of Support Service Living Unit projects, they should continue to be seen as a desirable option and a preferred means of obtaining independent living assistance for many disabled persons. However, members believe that future projects should not be of a size that they become mini-institutions. Efficiency considerations should not determine the lifestyle of residents.

Council encourages more active participation of residents in the management and administration of projects. Some residents already participate in management functions through involvement in performance evaluations of staff and such processes as management/ resident meetings. Some serve on the Board of Directors of their project or of another project, or on Board committees. It is in the best interests of everyone that more residents accept responsibilities which go along with the rights they have as service recipients.

Greater flexibility in the budget process is needed. This will allow management and staff increased

flexibility in adjusting to the fluctuating service needs of residents. The expansion of services (possibly in conjunction with the Outreach program) to include the workplace and other locations outside the project is also a high priority for Council. If employment equity is to become a reality for disabled persons, independent living assistance in the workplace is essential.

WE RECOMMEND:

5. **THAT FUTURE SUPPORT SERVICE LIVING UNIT PROJECTS SHOULD NOT BE OF A SIZE THAT THEY BECOME MINI-INSTITUTIONS.**

6. **THAT SERVICE RECIPIENTS SHOULD PARTICIPATE MORE ACTIVELY IN THE MANAGEMENT AND ADMINISTRATION OF SUPPORT SERVICE LIVING UNIT PROJECTS.**

7. **THAT GREATER FLEXIBILITY SHOULD BE INCORPORATED INTO THE BUDGET PROCESS FOR SUPPORT SERVICE LIVING UNIT PROJECTS.**

Outreach Attendant Care

In order for this program to meet the future needs of consumers, Council believes the shortcomings set out earlier in Chapter II must be eliminated. Disabled persons have also indicated that the program, even in its present form, is needed in all areas of the province and its speedy development must be encouraged.

Expansion of services available from the Outreach program appears to offer the most feasible means of

providing independent living assistance in the workplace, school or wherever required, to those individuals already receiving assistance within this program or from an S.S.L.U. project. Creative mechanisms will need to be developed by government, management, employers and consumers working together, to link the two programs and provide the necessary flexibility.

WE RECOMMEND:

8. **THAT EVERY EFFORT BE MADE TO IMPROVE THE DESIGN OF THE OUTREACH PROGRAM AND TO INCREASE ITS AVAILABILITY IN ALL AREAS OF THE PROVINCE.**

9. **THAT MECHANISMS BE DEVELOPED TO IMPROVE THE FLEXIBILITY AND PORTABILITY OF THE OUTREACH PROGRAM IN ORDER THAT INDEPENDENT LIVING ASSISTANCE CAN BE PROVIDED TO CONSUMERS OUTSIDE THEIR HOMES.**

The government of Ontario has announced its concern regarding employment equity and Council was pleased to be consulted about the I-Count survey which was carried out within the civil service in 1986. This survey looked at the employment patterns of disabled persons, women, native people, Francophones, racial and ethnic minorities in the Ontario public service. Council suggests that the public service would provide an excellent environment within which to test mechanisms to implement the provision of independent living assistance in the workplace.

WE RECOMMEND:

10. **THAT THE GOVERNMENT OF ONTARIO DESIGN AND INITIATE A PILOT PROJECT WITHIN THE PUBLIC SERVICE TO DELIVER INDEPENDENT LIVING ASSISTANCE IN THE WORKPLACE.**

The Direct Funding Option

If Council's vision is to be realized and disabled persons enabled to achieve control of the services they receive and freedom in their lifestyle, there is one additional and essential option required - the direct funding option.

Providing direct funding to individuals to enable them to acquire their own assistance is fundamental to the realization of Council's vision and reflects the desire of growing numbers of disabled persons in the province. It also reflects the undoubted ability and willingness of many individuals to assume responsibility for the management as well as the direction of their services.

The person who is provided with direct funding is free to purchase his/her independent living assistance from the most convenient source and can schedule the services to meet his/her needs. Independent Living Centres, Support Service Living Units and Transitional Living Centres are among the many resources that are available to an individual seeking to establish a personal support system.

Council's position is that direct funding, as a means of enabling disabled consumers to manage and direct their own independent living assistance, is a necessary and desirable option that should be available.

Council is also aware of the necessity for government to monitor any program to ensure that monies paid out are used wisely and properly by those receiving funding. Accountability is currently ensured through budget controls in programs such as Support Service Living Unit Projects and Outreach programs which are administered through non-profit corporations.

Council has reviewed materials from jurisdictions such as California which provide direct funding and has closely examined the Attendant Care Action Coalition's 1986 paper entitled Options for Independent Living Assistance. Council has also considered the Ontario Association for Community Living report Alternatives to Institutions. As indicated earlier, members have consulted many disabled persons and organizations serving them. Having studied this issue very carefully, Council feels that government should embark on the innovative development of mechanisms to provide direct funding to those disabled persons who are able and willing to manage and direct their own services.

Members say this after careful deliberation because of the perception by government of tremendous difficulties with individualized control over funding. As in the case of Support Service Living Units and the Outreach program, annual budgets will have to be developed with individual disabled persons and reviewed carefully to assess the appropriateness of both hours of service and funds required. Questions of accountability and mechanisms for the resolution of disputes must be dealt with for the benefit of everyone involved.

The review process must be flexible enough to respond quickly to the changing needs of individuals. It has been noted, for example, that many clients now using the Outreach program are disabled by multiple sclerosis. The development of multiple sclerosis often follows a "wave-like" pattern whereby an individual's needs for service can vary considerably. At times the client requires a relatively low level of service; at other times, the service needs may increase suddenly and considerably. This can also occur with various other disabling conditions. The review process must therefore allow for speedy adjustment to funding.

After the review has been completed, there are a number of ways by which monies could flow to individuals. Direct funding, voucher systems and funding through service-providing agencies pursuant to service contracts negotiated by the consumer, are ways that

have been successfully utilized in other jurisdictions. The Review of Support Service Needs currently being undertaken by the Ministry of Community and Social Services in consultation with interested groups and individuals should develop appropriate options in this area. A range of methods may be desirable to meet individual circumstances.

WE RECOMMEND:

11. **THAT CONSUMERS OF INDEPENDENT LIVING ASSISTANCE WHO WISH IT SHOULD BE PROVIDED WITH THE FUNDS TO ACQUIRE, MANAGE AND DIRECT THE SERVICES THAT MEET THEIR UNIQUE SUPPORT NEEDS.**

12. **THAT ANNUAL BUDGETS SHOULD BE ESTABLISHED FOR EACH INDIVIDUAL, SUBJECT TO SPEEDY REVIEW, TO ALLOW FOR CHANGING SERVICE NEEDS.**

13. **THAT THE REVIEW OF SUPPORT SERVICE NEEDS BEING UNDERTAKEN BY GOVERNMENT WITH INTERESTED GROUPS AND INDIVIDUALS SHOULD CONTINUE TO DEVELOP OPTIONAL METHODS OF FLOWING FUNDS TO INDIVIDUAL DISABLED PERSONS WHO ARE ABLE AND WILLING TO MANAGE AND DIRECT THEIR SERVICES.**

Funding of Family Members or Significant Others

It follows from our vision that those who control their own independent living assistance should have the right to choose who they want to provide them with assistance. Family members or significant others should not be disqualified automatically from becoming paid independent living assistants for disabled family members or friends. There are a number of situations in which such persons can provide the most satisfactory

and cost-effective assistance. In some cases, there may be no other alternative which would allow an individual to remain in his/her own home.

Council recognizes the need to foster and maintain traditional relationships within the family. Care must be taken to encourage families to continue to integrate disabled members into all aspects of normal family and neighbourhood life. An annual budget review will be necessary, not only to determine service needs but also to ensure the disabled person wishes to remain within the family home and is receiving the care for which payment is being made.

Council does not anticipate any major withdrawal of support presently being offered on a voluntary basis by family, friends or neighbours. Council sees voluntary help continuing but in some circumstances, it is appropriate that family members or friends be paid for their assistance.

Dependence on family or significant others for essential personal physical assistance can be embarrassing to the disabled person and often causes considerable stress and feelings of guilt. Similarly, the disabled person often feels that he or she has no control over the situation and cannot request that the

assistance be provided at the time or in the manner which the disabled person would prefer. This is stressful to any relationship.

There are also situations in which no alternative assistance is available either temporarily or, in some cases, permanently. The latter is common in smaller communities, rural areas and even areas in larger municipalities which are not easily accessible by public transit. The cost and loss of privacy associated with having a live-in attendant makes this a non-viable solution, especially in a family home without separated living quarters.

Many families are two-income or single-parent units. Where a spouse, parent or adult must remain at home to provide assistance, the family unit may undergo undue hardship. Financial problems can cause conflict and ultimately lead to family breakdown. Although payment to family must not become an automatic entitlement, if the disabled person is able to direct funds for necessary assistance to a family member or significant other, some of the stress and guilt may be alleviated. Control by the disabled person is re-established.

In a great many cases, personal care assistance is not something which can be scheduled for one or two large blocks of time during the day. More often, it is a

series of smaller tasks which must be performed at irregular intervals over a longer time period. It is often neither feasible nor cost-effective to bring in someone from outside the home to provide such services on an ongoing basis.

In short, there are many advantages to be gained from permitting payment to family members or significant others and only a minimal likelihood of abuse. Council recognizes the broader financial implications of this recommendation but feels the annual budget review would provide adequate cost control. The benefit to disabled persons would be entirely consistent with the government's thrust toward de-institutionalization.

WE RECOMMEND:

14. THAT INDIVIDUALS IN RECEIPT OF INDEPENDENT LIVING ASSISTANCE SHOULD BE ENABLED TO PAY ANYONE, INCLUDING FAMILY MEMBERS OR SIGNIFICANT OTHERS, FOR THE PROVISION OF SUPPORT SERVICES.

Brokering

Definitions of "brokerage" vary considerably, as the concept is still in the process of development. Given the current interest being expressed by many different groups, it seems probable that a number of models will emerge very quickly. A "brokerage" tends to be

interpreted as an entity in itself - an organization. Council prefers to use the term "brokering" instead, because an organization is not necessarily required. What disabled persons need are the services provided by an independent third-party facilitator, or broker.

The Attendant Care Action Coalition of Ontario has already started to look at the possibilities of developing brokering arrangements in the province, as has the Ontario Association for Community Living. Council encourages individuals, groups and government to continue to explore alternatives.

In order to develop a concept for a possible model, Council began by defining the following terms:

The Ministry: A ministry of the government of Ontario (e.g. Ministry of Community and Social Services) authorized to flow funds to clients requiring independent living assistance.

The Consumer: A client of the Ministry using independent living assistance services.

Service Providers: Those who provide independent living assistance; such as a non-profit organization which hires staff to provide services, or individuals who may be family members or significant others to a disabled person.

The Broker: A third party who finds independent living assistance services and provides varying levels of back-up support to the Consumer regarding the delivery of services.

Brokering: The action of a Broker in finding independent living assistance services. It is the process that a Broker is empowered by the Consumer to undertake, in finding/ negotiating for the provision of support services to the Consumer.

A range of models may have to be developed to suit the unique needs of individual Consumers and to utilize the varying resources in the locations where they choose to live. Not all disabled persons will choose to use the services of a Broker but in those situations where a Broker is used, Council believes it is essential that the Broker be separate and independent from the Ministry, the Consumer and the Service Providers.

In order to achieve this Council recommends that the Ministry adopt a policy of determining, on an annual basis, a fee for all Brokers across the province. This fee would be a percentage of the dollars allocated to each Consumer for the purchase of his/her independent living assistance. The allocation would be based on an annual review process and the percentage for the Broker's fee would be a variable add-on to the base budget, depending on the amount of support each Consumer requires from the Broker. The Ministry would retain a measure of control by fixing the percentage brokering fee and through negotiation in the annual review of hours of service required by the Consumer.

The Consumer would be free to choose a Broker and select the services negotiated for them by that Broker. He/she would control his/her budget either by flowing the dollars directly to the Brokers or Service Providers. Alternatively, the funds may be flowed directly from the Ministry to the Broker and to the Service Providers on the approval of the Consumer.

Those disabled persons who can manage and direct their own services may, from time to time, choose to use the services of a Broker or obtain emergency assistance through an Independent Living Centre. An allowance for this contingency will need to be made by the Consumer in building his/her annual budget.

The most important components of the Brokering concept are that, to the greatest extent possible, maximum control remains with the Consumer, in that the Ministry enables him/her to choose a Broker and choose a Service Provider, safe in the knowledge that the Broker is working on a pre-arranged fee and the Brokering is independent of the Ministry and the Service Providers.

Again, consultation between the Ministry, Consumers and Brokers will be essential and out of such consultation processes, methods of funding will evolve. For this reason Council does not believe it is appropriate to offer further comment on funding mechanisms at this time.

WE RECOMMEND:

15. **THAT THE GOVERNMENT OF ONTARIO, IN CONSULTATION WITH CONSUMERS AND INTERESTED COMMUNITY GROUPS, EXPLORE THE CONCEPT OF BROKERING AND DEVELOP MODELS TO BE TESTED IN BOTH RURAL AND URBAN AREAS OF THE PROVINCE.**

Advocacy

For some people there may be difficulties in assessing the various options within a range of service delivery programs and in accessing the one they want. Council recognizes this and believes that there is a role for an advocate.

Members are supportive of the concept of advocacy set out in You've Got A Friend, the report of the review of advocacy for vulnerable adults undertaken in 1987 by Father Sean O'Sullivan and his colleagues.

Independent Living Centres

As in brokering arrangements, Independent Living Centres attempt to link consumers with appropriate community services and provide information to individuals and community groups. The movement is flourishing in the United States and is developing in Canada. There are also Independent Living Centres functioning in England. We feel that Independent Living Centres have an integral part to play in

linking consumers with independent living services and their development should be encouraged throughout the province as a possible option for obtaining services.

An Independent Living Centre in Thunder Bay, for example, helps consumers find a range of services which will help them remain in their homes and with their families. In north-western Ontario, disabled people call the inability to obtain community services in small centres outside Thunder Bay, the "slippery slide to Thunder Bay" because many individuals have been, and are still being, separated from their communities so that their needs can be met. The same problem has been identified in other areas of the province and Council believes this should not happen in a caring society.

WE RECOMMEND:

16. THAT THE GOVERNMENT OF ONTARIO ENCOURAGE THE DEVELOPMENT OF INDEPENDENT LIVING CENTRES IN RURAL AND URBAN REGIONS OF THE PROVINCE.

Independent Living Assistance in the Workplace

Independent living assistance can also facilitate the movement of disabled persons into the workplace. If assistance is provided in the workplace, more disabled persons will have the opportunity to be employed. There are many methods by which assistance could be provided. If disabled persons are funded directly,

this allows them some options in the way they schedule the services they require. Alternatively, it may be more cost-effective for disabled individuals to co-ordinate and share support services in a place of employment through expansion of Support Service Living Unit funding or the Outreach program. Co-workers could also be paid to act as assistants in the workplace and employers could be compensated for any lost time through small subsidies from the provincial government, or by relief from taxation.

In the long run, costs will be offset by the increased productivity which disabled persons will bring to society. Council believes it is time to address, with some urgency, the complex problems associated with the provision of assistance in the workplace and urges government to take the initiative in addressing this issue with consumers, unions and major employers in the province.

WE RECOMMEND:

17. **THAT THE ONTARIO GOVERNMENT, IN CONSULTATION WITH CONSUMERS, UNIONS AND EMPLOYERS, DEVELOP AND TEST METHODS OF PROVIDING INDEPENDENT LIVING ASSISTANCE IN THE WORKPLACE.**

CHAPTER V

EDUCATION

Many consumers of independent living services have had little or no opportunity to acquire the skills associated with directing and managing the people providing their support services. Interpersonal skills are required in any employer/employee relationship and particular sensitivity is needed on both sides when dealing with personal and intimate services. These skills are required in addition, of course, to daily living skills such as budgeting and managing one's business affairs.

The Transition to Independent Living

Council believes there is a place and often a need for an orientation stage for consumers. This applies whether they are newly disabled, have been institutionalized for a lengthy period, or are moving away from home. Everyone needs to become fully aware of all the rights and responsibilities they have as consumer or employer. They should also be sensitized to the rights and responsibilities that their independent living assistants have as employees. This is equally applicable to consumers of services from Support Service Living Unit projects and Outreach as it is to consumers who directly employ assistants.

There are many ways in which persons can become familiar with the responsibilities of being both a consumer and an employer. Transitional Living Centres are one way of obtaining this kind of education. Council is aware of programs offered by Handicapped Action Group Incorporated (H.A.G.I.) in Thunder Bay, Bloorview, Bellwoods and the Gage Transitional Living Centre in Toronto. At the Gage, life skills training is provided at various levels before the resident moves out into the community. Education is offered at three levels:

Level 1. selfcare, cooking and housing skills;
Level 2. recreation and vocational skills;
Level 3. integration skills.

In addition to the skills mentioned above, many other issues have to be addressed when individuals are preparing to deal more directly with their independent living assistance needs. The Centre for Independent Living in Berkeley, California has developed a program which offers disabled persons guidance in finding and keeping an independent living assistant. Among the topics addressed are:

- "Assertiveness Training
- Selection and interviewing procedures including identification of specific needs, compatibility, identification of skills in prospective attendant

- Definition of rights and responsibilities of client and attendant
- Hiring procedures
- Defining duties - "being clear", "communication skills"
- Training attendant
- Time management
- Money management
- Record keeping
- Paying an attendant
- Evaluation procedures
- How to deal with: grievances; theft; firing attendant
- Job incentives to keep good attendants"(7)

This is an extensive list of study areas, but if an individual is to be an efficient and creative manager and/or director of his/her particular services, he/she must be well versed in the myriad administrative and social matters which can arise between assistant and consumer. Since the relationship that exists between consumer and assistant is an extremely personal one, many issues can arise which could put the relationship in jeopardy. Orientation training of consumers would help alleviate the severity of these problems by giving individuals a framework within which to analyze emerging problems and come to a resolution with his/her assistant.

It is important that there is a time frame within which an individual is expected to acquire this life skills education. This ensures that Transitional Living Centres do not become "holding tanks" and the expectation is clearly understood that individuals will

be able to move on to independent living in the community, where appropriate housing and services will be made available to them.

Independent brokers and the brokering system could play a significant role in the education of consumers. In their report Toward Independence: An Assessment of Federal Laws Affecting Persons with Disabilities - With Legislative Recommendations, (February 1986), the National Council on the Handicapped of the United States recommended that the following two points, among other things, be studied:

- "Comprehensive personal assistant services, including long-term, short-term (respite), and emergency attendants, readers, interpreters, and advocates for mentally retarded people.
- Case management assistance for independent living, including transition services from the hospital to the home, institution to community, and from parents' home to independence in the community; and assistance in equipment selection and maintenance, and in locating sources for other independent living support services."(8)

It is our belief that Transitional Living Centres and brokering services are appropriate ways for disabled persons to become acquainted with the responsibilities and challenges that are associated with independent living assistance. Community Colleges could also offer appropriate courses. Disabled persons, organizations

serving them and government should explore developing or adapting other programs to meet this need. Council's vision of independent living would include the opportunity to provide access to this type of education for anyone who needs it, in a variety of settings and locations across the province.

WE RECOMMEND:

18. **THAT EDUCATIONAL PROGRAMS, DESIGNED TO ENHANCE THE ABILITY OF INDIVIDUAL CONSUMERS TO DIRECT AND MANAGE THEIR SUPPORT SERVICES BE MADE AVAILABLE ACROSS THE PROVINCE IN TRANSITIONAL LIVING CENTRES, INDEPENDENT LIVING CENTRES OR COMMUNITY COLLEGES.**

Training of Independent Living Assistants

In December, 1985 this Council published a position paper entitled: Training Requirements For Attendant Care Workers. In that report, Council stated:

> "Chief among the matters of consensus was the fact that, at present, inadequate resources are available to provide appropriate training for those employed, or about to be employed, as attendants. What training is done at present tends to be done on an "in-house" basis, i.e. persons hired from a wide variety of backgrounds are given training by individual clients or by specific service providers, relevant to the specific needs of the client(s) involved. At present, however, funds for such training are extremely limited, to the point where, in many cases, attendants are in fact required to learn the job "on the run". The result is that training is often inadequate at best, and persons who might with help develop into fine attendants fail to do so because of the inadequacy of training opportunities. Moreover, because individual attendant care needs vary so greatly, and the role of an attendant is very difficult to define with

> precision, both individual clients and agencies report real difficulties finding suitable candidates for employment as attendants."(9)

There are many issues ranging from credentialism to sexuality which must be addressed in this area. Independent living assistants "need to learn basic principles they can use to help all disabled individuals. At the same time they need to develop specific skills that meet the needs of different individuals".(10)

Council also believes that assistants have a right to reasonable wages, good working conditions and consistent hours. To the greatest extent possible, independent living assistants must have the same rights and responsibilities as any other salaried worker. However, the very nature of the occupation makes it uniquely personal. In group homes and S.S.L.U. projects, where they have not already been established, standards must be developed and evaluation processes established to allow the service recipient to assess the job performance of staff.

Council has reviewed the preliminary findings of an interministerial committee of the Ontario government relating to Visiting Homemaker Services and has noted similarities in many of the staffing issues addressed. That committee is considering an annual review of wages

for visiting homemakers to determine wage adjustments on a province-wide basis. A similar annual review of funding to individuals who manage and direct their own independent living assistance or to agencies which provide such services, seems appropriate to Council.

Members believe that such an annual review should allow for some merit and cost of living adjustments within set salary scales. Funding provided within a budget for wages and benefits, as well as staff training, should also be protected from encroachment by other items approved in the budget so that consistency in this area will be maintained throughout the province.

Initiatives such as the foregoing would make the job of an independent living assistant more attractive and help reduce staff turnover.

Training programs should be developed for the independent living assistant to learn more about his/her profession and create the opportunity for advancement. The training should be available both "in-house" and through more formal education opportunities independent of the workplace.

Council is aware that some community colleges are implementing programs for assistants and has concerns regarding the length of these courses and the

counselling offered to students regarding their future employment expectations and their role in the lives of service recipients. Many persons who provide excellent assistance to disabled persons would not be eligible for, or interested in, such courses. It would be disastrous for consumers if this lack of a paper "qualification" precluded such individuals from working as independent living assistants.

Council acknowledges that training should be available to those who wish to avail themselves of an opportunity to acquire skills of a practical nature or related to essential communication abilities, but questions whether 1 or 2-year courses are necessary for such purposes or represent the wisest use of tax dollars. However, for those staff who work or intend to work with more severely disabled persons requiring assistance with decision making and the direction of their services, Council acknowledges that more extensive training may be appropriate.

Since in many cases the assistant will be working closely with the disabled person and largely under under his/ner direction, it is difficult to see the justification for establishing lengthy courses for all assistants. Initial training that can be supplemented by short, subject specific courses, would seem more useful and cost-effective. Such courses would allow an

assistant to select specific areas of interest and, possibly, the enhancement of skills which would enable him/her to progress to management level in an organization providing services. Council also recommends that disabled persons should be invited to join the teaching staff for a substantial segment of the programs and be closely involved in the course design.

Council continues to believe that:

- **The primary focus of training for assistants should remain with the client and/or service provider.**
- **The Ministry of Community and Social Services should explore ways and means of delivering increased funding for clients and/or service providers wishing to provide training for assistants in their employ.**
- **The Ministry of Community and Social Services should maintain its present practice whereby the funding of Support Service Living Units and Outreach Attendant Care Programs shall not be contingent upon the hiring of assistants with academic or professional accreditation.**
- **Insofar as it is possible, the relationship between a client and his/her assistant should be an individual one, with as little involvement of external agencies as is realistically possible.**(11)

Ultimately, we do not feel that any one way of training an independent living assistant is correct. The important factor is emphasis on the mutual respect of both the consumer and the assistant.

WE RECOMMEND:

19. THAT THOSE EMPLOYED AS INDEPENDENT LIVING ASSISTANTS BE ACCORDED ALL THE RIGHTS OF AN EMPLOYEE, INCLUDING ACCESS TO JOB TRAINING PROGRAMS AND JOB ADVANCEMENT WHERE POSSIBLE.

20. THAT FUNDING, WHETHER TO INDIVIDUALS OR ORGANIZATIONS PROVIDING INDEPENDENT LIVING ASSISTANCE, SHOULD BE REVIEWED ANNUALLY ON A PROVINCE WIDE BASIS IN A MANNER SIMILAR TO THAT PRESENTLY PROPOSED FOR VISITING HOMEMAKER SERVICES. THE REVIEW SHOULD ALLOW FOR SOME MERIT AND COST OF LIVING ADJUSTMENTS WITHIN SET SALARY SCALES.

21. THAT THE PORTION OF FUNDING ALLOCATED FOR WAGES, BENEFITS AND TRAINING OF STAFF SHOULD BE PROTECTED WITHIN THE BUDGET FROM ENCROACHMENT BY OTHER EXPENDITURES.

CHAPTER VI

CONCLUSION

Council believes that it is time to move toward a system that recognizes the rights of individuals to have as much control as possible over the provision of their own services. Furthermore, independent living assistance should be available in all settings of daily life, including the workplace.

While Council realizes that many individuals will always need support in determining and/or managing the services they require, its vision of independent living assistance is one which would allow freedom of choice. To achieve this vision, Council believes the option of direct funding should be made available to those individuals who are able and willing to manage and direct their own independent living services.

With this evolution toward as much independence as possible, members recognize the government's concern about direct funding. With control comes responsibility. Appropriate non-intrusive monitoring mechanisms can be developed by government and consumers jointly to ensure that the consumer is using funds prudently. Given such mechanisms, we feel that the

consumer should be allowed to hire anyone as his/her independent living assistant. This should include parents, spouses or significant others with whom the consumer might live.

Council also believes that there needs to be exploration of how government could most appropriately direct funds to the consumer. There are several ways in which this could be done. Voucher systems, direct individual funding and funding through service-providing agencies are but a few examples.

Persons who require independent living assistance should have the opportunity to become familiar with the rights and responsibilities of being both a consumer and an employer. Educational programs, transitional experiences and brokering are useful devices for obtaining information about managing and directing services, and using other community resources. Council also is concerned that independent living assistants be treated and respected as valuable employees. Such understanding will flow from consumer education and appropriately educated and sensitized assistants.

Council believes that there is an opportunity for government, service providers, consumers and educators, working together, to develop innovative and appropriate ways to train assistants. This is an essential

component of any independent living assistance program. Council believes that to live independently is a fundamental human right. It is time to see disabled persons as a diverse population whose members often have very different needs, desires and lifestyles.

Let us go into the future as a society united in our diversity. Let us have the range of services which will allow all Ontarians to achieve this vision and let us acknowledge that for independent living, the time is now.

- - - - -

END NOTES

1. The Sub-Committee on the Disabled and the Handicapped of the Standing Committee on Communications and Culture. Challenge: Putting Our House In Order. Ottawa, 1987. p.5.

2. Ministry of Community and Social Services. Evaluation of the Outreach Attendant Care Program. Toronto, 1986. p.5.

3. International Center for the Disabled. The ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream. New York, 1986. p.67

4. Ministry of Community and Social Services. Draft Guidelines for Family Relief Programs. Toronto, 1986. p.5.

5. Adolf D. Ratzka. Independent Living and Attendant Care In Sweden: A Consumer Perspective. New York, 1986. p.8.

6. World Institute on Disability. Attending To America: Personal Assistance For Independent Living. Berkely, 1987. p.1.

7. Zukas, Hale, Cone, Kitty and Leon, Joan. Descriptive Analysis of the In-Home Supportive Services Programs in California. Berkeley: World Institute on Disability, 1985. p.21

8. National Council On The Handicapped. Toward Independence: An Assessment of Federal Laws and Programs Affecting Persons With Disabilities - With Legislative Recommendations. Washington, 1986. p.46.

9. Ontario Advisory Council On The Physically Handicapped. Position Paper on Training Requirements for Attendant Care Workers. Toronto, 1985. p.1.

10. Nova Scotia Homes for Independent Living: Attendant Training Resource Package. Halifax, 1987. p.1.

11. Ontario Advisory Council for the Physically Handicapped. op.cit. pp.4-5.

B I B L I O G R A P H Y

CANADA - ONTARIO SOURCES

Andersen Management Services Inc. Ontario March of Dimes Vocational Rehabilitation Research Study. Thunder Bay, 1987.

Attendant Care Action Coalition. Independent Living Assistance Brokerage: A Pilot Project Proposal. Toronto, 1987.

Attendant Care Action Coalition. Options for Independent Living Assistance. Toronto, 1986.

Avebury Research and Consulting Ltd. Planning for Diversity. A Study of the Recruitment and AdAdvancement Policies and Practices in the Ontario Civil Service. Toronto, 1987.

Avenue II Community Program Services. Program Description - Supported Independent Living Program. Thunder Bay, 1987.

Bleasdale, Joelle. Cheshire Homes of London Inc: Consumer Satisfaction Survey. London: Ministry of Community and Social Services, 1987.

Bloorview News: Annual Newsletter 1986. Toronto, 1987.

Canadian Hearing Society of Thunder Bay. Brief Presented to the Ontario Advisory Council for Disabled Persons. Thunder Bay, 1987.

Cheshire Homes Foundation. The Evolution of Support Service Projects in Ontario. Toronto, 1984.

Cheshire Homes of London Inc. A Model for Providing Attendant Care in Urban and Rural Settings. London, 1987.

Cheshire Homes of London Inc. Employees Handbook. London, 1985.

Cheshire Homes of London Inc. Position Description: Support Care Worker. London, 1987.

The Community Interaction Association of Sault Ste. Marie. Submission To The Ontario Advisory Council for Disabled Persons. Thunder Bay, 1987.

Dagsvik, Jo-Anne. Correspondence. Thunder Bay: The Canadian Red Cross Society, 1987.

Denton, Margaret A., and Davis, Christine K. Patterns of Supports: The Use of Support Services Among Senior Public Housing Tenants In Ontario. Hamilton: Social Data Research Limited, 1986.

Edgar, Bruce. Correspondence. Thunder Bay: Hogarth-Westmount Hospital, 1987.

The Gage Transitional Living Centre. Information Sheet. Toronto, 1985.

George Brown College of Applied Arts and Technology. Support Care: Program Proposal. Toronto, 1985.

Grist, Pat. "Options for Independence/Hiring and Supervising Your Attendant". Connections Toronto: The Muscular Dystrophy Association of Canada, March, 1987. pp. 10-14.

Handicapped Action Group Incorporated. Annual Report - 1986. Thunder Bay, 1987.

Handicapped Action Group Incorporated. Directory. Thunder Bay, 1987.

Horner, Bill. Ontario Attendant Care Service Delivery System - "Essential Or Not". Thunder Bay, 1987.

Human Resources Secretariat. Employment Equity Database. Service-wide Counts Analysis. Toronto, 1987.

Human Resources Secretariat. I Count for Equality in Employment. Toronto, 1987.

Independent Living Centre (Kitchener-Waterloo). Apartment Project. Kitchener, 1986.

Independent Living Centre (Kitchener-Waterloo). Outreach Attendant Care Program. Kitchener, 1986.

Independent Living Centre (Kitchener-Waterloo). Peer Resource Enrichment Program. Kitchener, 1986.

Independent Living Centre (Kitchener-Waterloo). Temporary Personal Support Care. Kitchener, 1986.

Kinninnen, Elise. Bellwoods Park House Tenant Information Book. Toronto: The John Yaremko Centre for Community Living, 1987.

Lakehead Social Planning Council. People Helping People. Thunder Bay, 1987.

Lanz, Susan. Correspondence. Toronto: Cheshire Homes Foundation of Canada Inc, 1985.

Lauder, Jean. History of Bellwoods Park House. Toronto: The John Yaremko Centre for Community Living, 1983.

Manitouwadge Handi-Action Group. Brief Presented to the Ontario Advisory Council for Disabled Persons. Thunder Bay, 1987.

Ministry of Community and Social Services. Challenges and Opportunities: Community Living for People with Developmental Handicaps. Toronto, 1987.

Ministry of Community and Social Services. Corporate Plan. Toronto, 1987.

Ministry of Community and Social Services. Draft Guidelines for Family Relief Programs. Toronto, 1986.

Ministry of Community and Social Services. Draft Report of the Interministerial Committee on Visiting Homemaker Services. Toronto, 1987.

Ministry of Community and Social Services. Evaluation Of The Outreach Attendent Care Program. Toronto, 1986.

Ministry of Community and Social Services. Family Benefits Manual. Toronto, 1987.

Ministry of Community and Social Services. Outreach Attendant Care Year End Report, 1985/86. Toronto, 1986.

Ministry of Community and Social Services. Support Service Living Units Year End Program Update, 1985/86. Toronto, 1986.

Ministry of Community and Social Services. Support Services for Physically Disabled Adults. Toronto, 1983.

Ministry of Health. Home Care Program. Toronto, 1985.

Niagara District Health Council. Services For Young Physically Disabled Persons In Niagara: A Proposal. Thorold, 1987.

Office For Senior Citizens Affairs. A New Agenda: Health and Social Services Strategies for Ontario Seniors. Toronto, 1986.

Office for Senior Citizens' Affairs. One-Stop Access-or-An Integrated Approach To Community Health and Social Services. Toronto, Winter 1987.

Ontario Advisory Council for Disabled Persons. Independent Living In The Community: Report On Thunder Bay Consultation. Toronto, 1987.

Ontario Advisory Council on the Physically Handicapped. A Strategic Plan for 1986/87. Toronto, 1986.

Ontario Advisory Council on the Physically Handicapped. Position Paper on Individual Attendant Care. Toronto, 1982.

Ontario Advisory Council on the Physically Handicapped. Training Requirements for Attendant Care Workers. Toronto, 1985.

Ontario Advisory Councils on the Physically Handicapped and Senior Citizens. The Freedom To Move Is Life Itself: A Report On Transportation In Ontario. Toronto, 1987.

The Ontario Association for Community Living. Alternatives To Institutions. Toronto, 1987.

O'Sullivan Rev. Sean et al. You've Got A Friend: A Review of Advocacy in Ontario. Toronto: The Government of Ontario, 1987.

Ottawa-Carleton Regional District Health Council. Final Report: Accommodation and Support Care Needs of the Severely Physically Disabled in Ottawa-Carleton. Ottawa, 1984.

The Physically Handicapped Adults Residence Association. "For Your Information". Nipissing - Parry Sound, 1987.

Tercentennial Lodge. Information Sheet. Kingston, 1987.

Terrace Bay-Schreiber Disability Action Group. Brief Presented to the Ontario Advisory Council for Disabled Persons. Thunder Bay, 1987.

School of Continuing Education - Health Sciences Section. Assisting the Physically Disabled At Home. Ottawa: Algonquin College, 1986.

The Sub-Committee on the Disabled and the Handicapped of the Standing Committee on Communications and Culture. Challenge: Putting Our House In Order. Ottawa, 1987.

Sweeney, Honourable John. Minister's Newsletter. Toronto: Ministry of Community and Social Services, August, 1987.

CANADA: FEDERAL, OTHER PROVINCES AND PRIVATE SOURCES

Boyer, J. Patrick et al. Equality For All: Report of the Parliamentary Committee on Equality Rights. Ottawa, 1986.

The Canadian Medical Association. Health Care for the Elderly: Today's Challenges, Tomorrow's Options. Ottawa, 1987.

Community Living Society of British Columbia. An Exploration Of The Concept of Service Brokerage: Providing Individuals With Choices. Vancouver, 1987.

Community Living Society of British Columbia. Brokerage. Vancouver, 1983.

Community Living Society of British Columbia. General Service Plan. Vancouver, 1983.

Dubas, S.P. Correspondence. Vancouver: Ministry of Health, 1986.

D'Aubin, April (ed.). Defining The Parameters Of Independent Living. Winnipeg: Coalition of Provincial Organisations of the Handicapped, 1985.

Department of the Secretary of State of Canada. Directory of Federal Services: Disabled Persons - 1987. Ottawa, 1987.

Department of the Secretary of State of Canada. Obstacles: 1987 Report Update. Ottawa, 1987.

Government of Canada. Accepting the Challenge: Government's Response to the Standing Committee on the Status of Disabled Persons. Ottawa, 1987.

Government of Canada. Toward Equality: The Response to the Report of the Parliamentary Committee on Equality Rights. Ottawa, 1986.

Hatfield, Honourable Richard. Correspondence. Frederickton: Office of the Premier, 1986.

Homes for Independent Living (Nova Scotia). Policy Manual: Residents Handbook. Halifax, 1986.

Lawlor, Karen. Correspondence. Winnipeg: Ministry of Community Services, 1986.

Lord, John and Osborne-Way, Lynn. Toward Independence and Community: A Qualitative Study of Independent Living Centres in Canada. Ottawa: Department of the Secretary of State of Canada, 1987.

Statistics Canada. Report of the Canadian Health and Disability Survey, 1983-1984. Ottawa, 1986.

Quinlan, Jerome. Correspondence. St. John's: Department of Social Services, 1986.

Veteran's Affairs Canada. Veterans Independence Program. Ottawa, 1987.

Walter Dinsdale Disability Service Information Centre. Attendant Care Registry. Calgary, 1987.

UNITED STATES SOURCES

Boston Center for Independent Living Inc. 1984-85 Annual Report. BCIL: A Ten Year Perspective. Boston, 1985.

Boston Center for Independent Living. Roll Call. Boston, March, 1987.

DeJong, Gerben. Environmental Accessibility and Independent Living Outcomes: Directions for Disability Policy and Research. East Lansing: Michigan State University, 1981.

Home Care Services for Independent Living, Inc. Client Handbook. Brooklyn, 1986.

Home Care Services for Independent Living Inc. Home Attendant Manual. Brooklyn, 1986.

International Center for The Disabled. The ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream. New York, 1986.

Litvak, Simi, Zukas, Hale and Heumann, Judith E. Attending to America: Personal Assistance for Independent Living. A Survey of Attendant Service Programs in the United States for People of All Ages with Disabilities. Berkeley: World Institute on Disability, 1987.

McQuade, Denise Ann. Correspondence. Brooklyn: Independent Living for The Handicapped Inc., 1987.

National Council On Independent Living. Independent Living Centers At A Glance. Chicago, 1987.

National Council On The Handicapped. Personal Assistance: Attendant Services, Readers and Interpreters. Washington, 1986.

National Council on the Handicapped. Toward Independence: An Assessment of Federal Law and Programs Affecting Persons With Disabilities - With Legislative Recommendations. Washington, 1986.

Ratzka, Adolf D. Independent Living And Attendant Care In Sweden: A Consumer Perspective. New York: World Rehabilitation Fund, 1986.

Ratzka, Adolf D. Swedish Attendant Care Programs for the Disabled and Elderly: Description, Analyses and Research Issues from a Consumer Perspective. Berkeley: World Institute on Disabled, 1984.

Rosen, Allan. Correspondence. Brooklyn: Home Care Services for Independent Living Inc., 1987.

Shreve, Maggie. The Movement For Independent Living. Chicago: National Council on Independent Living, 1987.

United States Commission on Civil Rights. Accommodating the Spectrum of Individual Abilities. Washington, 1983.

World Institute on Disability. Attendant Services Network: Personal Assistance for Independent Living. Berkeley, vol.1, 1987.

World Institute on Disability. International Services. Berkeley, 1986.

World Institute on Disability. Promotion Of The Independent Living Philosophy. Berkeley, 1986.

World Institute on Disability. The Resource Center On Attendant Services At The World Institute on Disbility. Berkeley, 1986.

Zola, Irving. Correspondence. Waltham: Brandeis University, 1987.

Zukas, Hale, Cone, Kitty and Leon, Joan. Descriptive Analysis Of The In-Home Supportive Services Program In California. Berkeley: World Institute On Disability, 1986.

BRITISH AND OTHER INTERNATIONAL SOURCES

Exeter Council for Independent Living. Summary of Services. Exeter, 1987.

Derbyshire Centre for Integrated Living. Information Sheet. Derbyshire, 1987.

Greenwich Association of Disabled People. Information Sheet. Woolwich, 1987.

Hampshire Centre for Independent Living. Information Sheet. Hampshire, 1987.

Hurst, Rachel. Correspondence. London: British Council of Organisations of Disabled Persons, 1987.

Southampton Centre for Independent Living. Information Sheet. Southampton, 1987.

The United Nations. World Programme of Action Concerning Disabled Persons. New York, 1983.